



March 30, 2016

I am writing in response to the letter of March 23 from Marsha Blackburn, Chairman of the Select Investigative Panel of the House Committee on Energy and Commerce. In that letter, Chairman Blackburn posed three questions regarding my testimony at the March 2, 2016 hearing on "Bioethics and Fetal Tissue." Below you will find the three questions and my responses.

Question: In response to a question (referencing exhibits A-3 and C1-2) about whether a woman considering donating fetal tissue should know "specifically what it's going for and what the specific tissues to be used are going to be?" you replied "I'm not sure". Is it not true that providing such information would allow a woman to make a more informed choice before choosing to donate fetal tissue?

Also, identify any ethical concerns you have in regards to exhibit A-3, with particular focus on the following statement: "Research using the blood from pregnant women and tissue that has been aborted has been used to treat and find a cure for such diseases as diabetes, Parkinson's, Alzheimer's disease, cancer, and AIDS". Do you agree with Dr. Goldstein that this is a deceptive representation?

Response:

Consent is a process and a conversation. The forms are documentation of that process, but not the consent itself, and are not necessarily a complete representation of the information given or the conversations had in the process of obtaining consent. I cannot confirm or deny your interpretation of Dr. Goldstein's views, but for my own part, I find the forms to be accurate though perhaps not ideally written. These tissues have indeed been used to try to treat and cure diseases, as described, but there could be more emphasis on the fact that these diseases have not been conquered. Of course, most people are fully aware that these diseases have not yet been cured.

Overall, I know of no evidence that any woman chose to donate when further information of this sort would have altered her decision. As to the specificity of tissues and uses, it is worth noting that the Reagan panel recommendations and the federal rules both forbid "directed donation," precisely to avoid unduly influencing a woman in her decision to donate tissue. As a general matter, tissue may be collected in a wide variety of circumstances from living adults and from cadavers, with consent for its use in broadly defined areas of research.

Question: When asked whether any business or clinic should sell fetal tissue for a profit, you stated, "It is against the law." Do you think it is unethical for a business or clinic to sell fetal tissue for a profit?

Response: It is unethical to violate the law, which states that fetal tissue may not be sold for a profit.



Question: In response to a question about cosmetics and the use of fetal tissue, you testified, "I find the cosmetic uses (not skin grafts) in Hollywood sometimes to be so frivolous that I'd be perfectly happy to see us abandon them." Please elaborate as to which uses of fetal tissue for cosmetic purposes (lotions, aging cream, etc.) you believe to be frivolous. Is fetal tissue used for other purposes that you believe does not represent a compelling public interest? If so, please identify these uses.

Response: I am unaware of any cosmetic uses of fetal tissue. In my responses to both of the questions concerning cosmetic uses, I spoke specifically about the full range of human tissues that are collected, which includes tissues collected from adult cadavers. Personally, I find some cosmetic uses of tissue from adult cadavers, for such things as lip plumping for persons who do not have an injury or other disfiguration, to be frivolous. I do understand, though, that these applications are legal.

Thank you for the opportunity to expand upon my testimony.

Very truly yours,

A handwritten signature in blue ink, reading 'R. Alta Charo'.

R. Alta Charo
Warren P. Knowles Professor of Law and Bioethics